Disentangling family life and hair pulling

DISENTANGLING FAMILY LIFE AND HAIR PULLING:

TRICHOTILLOMANIA AND RELATEDNESS

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Abstract

Trichotillomania (hair pulling) remains a relatively unknown form of body-focused repetitive behavior (BFRB). Sufferers tend to conceal both the action and its effects from others because of stigmatization, which is strong in both public and domestic spheres. Negative responses from close family members can add significantly to the suffering. Based on fieldwork in the UK and US, we explore how hair pulling troubles ties even among close family members. We show why ethnographic methods reveal impacts of hair pulling that structured assessments do not yet capture, and argue for a more nuanced study of BFRBs through anthropologies of relatedness.

Keywords

United Kingdom, United States, family relations, hair pulling, relatedness, trichotillomania,

Running Title

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Media Teaser

How do parents in the United Kingdom and United States deal with children who cannot stop pulling out their hair?

Bionotes

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Hair pulling disorder, or trichotillomania, is intertwined with family life in complex ways. The condition affects family relations, and family relations influence how the condition is experienced. In this article, we disentangle some of the connections between trichotillomania and family life, showing how this little-understood condition produces tensions within families, yet also how kinship ties can take sufferers closer to acceptance and recovery. Our ethnography of trichotillomania in the UK and the US will highlight some of the complications within families and the ways in which relatedness can transform people's experiences of living with this disorder.

In the following, we offer perspectives from mothers and fathers of hair pulling children, showing how gendered expectations from parents towards their children can affect experiences of trichotillomania, and how these experiences can affect families across generations. While our focus is the parent/child relationship, we also consider why support groups are seen as "families" by our informants, and how these groups can offer support in ways that family members cannot. By building on anthropological notions of relatedness, we argue that the bonds created by trichotillomania support groups can improve the relations in families.

"The most common disorder you've never heard of"

Trichotillomania (nicknamed "trich") is a form of body-focused repetitive behavior (BFRB). The most common BFRBs include hair pulling, skin picking and nail biting, and are thought to affect up to four percent of the population. The term "trichotillomania" was first coined by the French dermatologist Hallopeau in 1889 to describe the abnormal pulling out of body hair (Stein and Christenson 1999:2), but there is some evidence of BFRBs appearing in

Hippocratic corpus as early as 400BC (Kim 2014). Broader awareness of the pathophysiology of trichotillomania is recent, and to date there is limited understanding into its cause (Murphy and Flessner 2017). Trichotillomania first appeared in the DSM III-R (American Psychiatric Association 1987) as an "impulse-control disorder not elsewhere classified". It was re-classified in DSM-5 as an "obsessive-compulsive and related disorder" (American Psychiatric Association 2013).

Currently, hair pulling advocacy groups push a new label, "body-focused repetitive behaviors," because of their dissatisfaction with psychiatric classifications (Stein et al. 2010). In this article, we reflect this grassroots preference for "BFRBs," alongside the established psychiatric term "trichotillomania." The growing acceptance of the BFRB label is an instance of what Ian Hacking (1995) describes as a "looping" effect, that is, a change of a diagnostic label in response to the concerns of those living with it. Comparatively low medical awareness of trichotillomania is mirrored by a lack of awareness of BFRBs among lay people. A recent documentary film, "Trichster" (2015), dubbed trichotillomania "the most common disorder you've never heard of." For people living with trichotillomania, confusion, silence and stigmatization shape their daily experiences and people go to great lengths to conceal both the behavior and its results.

The psychiatric and medical view of BFRBs is often negatively focused on pathology, but people living with these behaviors commonly have positive experiences as well. The embodiment of BFRBs is highly sensory and varies from person to person. While often mistaken as self-harm, people living with trich rarely describe it as painful, and our respondents unanimously rejected the description of "self-harm" as assumed by doctors. Instead, they described their behavior as pleasurable and as making them feel relaxed and

happy. Indeed, the notion of "self-harm" as invariably pathological is increasingly contested within psychiatry (Chandler et al. 2011), and studies suggest that pain is not an essential part of self-harmful behaviours (Hicks and Hinck 2008; Hodgson 2004; Jacobson and Gould 2007). Further, while the results of the behavior are usually perceived as negative by sufferers as well as others, the act of pulling hair itself is more often a source of pleasure.

The heterogeneous experiences of BFRBs, and subtle individual differences, trouble not only the existing diagnostic criteria but also the choices for therapeutic intervention (Christenson and Crow 1996; Duke et al. 2010; Stein et al. 2010). When asked about their desire for a medical cure for hair pulling, several of our respondents said that they would not choose a "magic bullet" to take it away: "I wouldn't want to change it." People cherished their condition for increasing their empathy for suffering others: "If I didn't have this then I wouldn't have learned how to have empathy for other people;" a heightened sense of their own selves: "I wouldn't be the strong person I am today;" and the intense bonding experiences with other sufferers: "I would never have met all these amazing people." These enjoyable and paradoxically meaningful experiences of hair pulling are what family members find most difficult to comprehend.

Most of the literature on kinship assumes that reciprocal care is the norm (Sahlins 2011), especially in parent-child relations (Gottlieb 2000; Holloway et al. 2010; Stansbury et al. 2000). Therefore, family members could be expected to be the first to realize if another family is pulling out their hair, and would usually be in the best position to offer help. But shame and lack of awareness can hinder this, and instead of being supportive, families can significantly contribute to a deepening of the suffering.

Stigma is usually conceptualized as a management of spoiled identity in the *public* sphere (Goffman 2009), but rarely studied in *domestic* spheres. But stigmatization happens not only in public, it also happens at home (Marcks et al. 2005). Hence, stigma must also be studied as "being located in the intersubjective space—in the interpersonal actions and communications that signal recognition of shame—between patients and their closest family members" (Yang et al. 2007:1532). Among our respondents, managing the stigma of hair pulling emphatically starts at home.

The stigmatization of trichotillomania is heightened by the unusual nature of the condition, which includes the sudden urge to pull out one's own hair, and the inability to stop despite one's will to stop. Studies in psychiatry and psychology found that higher levels of embarrassment about the condition, and higher efforts at concealing the behaviour and its effects, are correlated with lower levels of trying to seek medical help (Chamberlain et al. 2007; Swedo and Rapoport 1991). Attempts to conceal trichotillomania are characteristic of the condition, making it similar to eating disorders (Swedo and Rapoport 1991) and body dysmorphic disorder (Schnackenberg and Petro 2016). Lay people tend to misrecognize hair pulling as a personal quirk rather than as a health problem.

For people with BFRBs, the realization that their behavior is not just a "weird" habit but a medically recognized disorder is a major life event. The insight that their behavior "has a name" and is practiced by many others transforms their experience of the behavior. The labelling also transforms how people learn about their condition and start to connect with others who share their experiences, comparable to discovering long-lost or hitherto unknown family relatives (Solomon 2012). We discuss this phenomenon of experiencing family-like bonds among BFRB sufferers at length in this article.

The bulk of the psychiatric literature treats trichotillomania as the compulsive behavior of an individual, and both its causes and its treatments are located within individual brains, leaving family dynamics as an unknown. Trich research has not yet explored family relations to the same extent as has been the case for other mental illness conditions (Clausen and Yarrow 1955, Hatfield and Lefley 1987, Yang and Kleinman 2008). The evidence on whether families with a trich child are functioning better or worse than other families is, so far, inconclusive (Moore et al. 2009). Some studies on family functioning in relation to hair pulling argue that lower levels of family functioning are correlated with high levels of suffering. Franklin and colleagues (2011) mention that trichotillomania can "negatively impact family functioning" due to tensions and strenuous efforts at concealment, but whether trichotillomania puts a strain on families, or whether the strains present in families have a causal role in the experience of trichotillomania, remains unclear. Using structured assessments to measure the perceived quality of family ties, Keuthen and colleagues (2013) argue that intrafamily stress and lack of support are correlated with higher distress due to trichotillomania. Hair pulling among children and adolescents is, in this regard, like other conditions, such as anxiety (Wood et al. 2003), obsessive compulsive disorders (Hibbs et al. 1991), or depression (George et al. 2006), which are all more severe when families are "unhappy" and "unsupportive." Yet psychiatric research on the nexus between family life and trich is not yet conclusive; rather, "diagnostic status did not predict family functioning nor did family functioning predict HPD [hair pulling disorder] pulling styles" (Murphy et al. 2017:34).

The existing literature lacks not only depth but also methodological and conceptual diversity: if any research on trich and family exists at all, it comes from psychology and

psychiatry, but not from other fields. Only two studies have explored domestic coping with hair pulling with qualitative methods, and these studies are limited to one kind of family member, either the trich sufferers (Boughn and Holdom 2003) or the parents of trich sufferers (Stevens and O'Conner-Von 2016), without exploring parents and children together and in interaction with each other. The present article is the first anthropological study on trichotillomania, using a range of qualitative methods and simultaneously considering both children and parents. We present ethnographic insights in dialogue with findings from psy research as well as from anthropologies of mental health and domestic worlds (Ecks 2010; Ecks and Kupfer 2015).

METHODOLOGY

This article is based on ethnographic fieldwork with trichotillomania sufferers by one of the authors, Bridget Bradley. Instead of measuring family functioning through structured assessments of trichotillomania, as most existing studies do, we take an open-ended approach to the problem and try to tease out how "family" comes to bear on the experience of hair pulling in a variety of ways. In 2015 and 2016, Bradley conducted 16 months of fieldwork with people living with BFRBs in the United Kingdom and United States. Fieldwork in the UK included interviews and interactions with a total of 43 research participants, including partners (5) and professionals dealing with the disorder (3), as well as those living with BFRBs (35). In the US, 22 people were interviewed, including clients (9), parents (5) and professionals (7) at two conferences for people living and working with BFRBs run by the TLC Foundation for Body-Focused Repetitive Behaviors (TLC), and at a leading Behavior Therapy Center in Washington, DC. Semi-structured interviews were audio-recorded in

public spaces and private homes. In a second phase of research, Bradley conducted further interviews with 19 key informants and undertook participant observation at home, at work, and in support groups.

A key feature of the fieldwork was to investigate the perspectives of family members and practitioners dealing with BFRBs. In addition to fieldwork with sufferers in the UK and in the US, Bradley spent one week in Dallas to conduct interviews at a BFRB conference for family members run by TLC, and one week at a Behavior Therapy Center in Washington, DC to interview clients and therapists who work closely with TLC. Bradley gathered her first findings at a TLC conference in Washington, DC in April 2015. Aware of the advances in BFRB support and treatments in the US, she decided to conduct further fieldwork to allow for comparisons between BFRB experiences in the UK and in the US. Throughout fieldwork, Bradley worked closely with the TLC Foundation to increase the support options available for those living within the UK. As part of this, she established the UK's first ever BFRB support groups during her fieldwork, setting up and running groups in Edinburgh and London. She continues to be involved with these groups each month and to raise awareness for BFRBs through public engagement.

Access and rapport with respondents was influenced by the fact that Bradley also suffers from trichotillomania, and she was continually struck by how people related to her and how easily and comfortably they seemed to open up. On several occasions, people told Bradley about their experiences with trichotillomania that they said they had never mentioned to anyone else before, including their closest family members. This contrasted with a perceived lack of empathy from medical professionals who were often said to "not understand" and therefore be "unable to help." Bradley's positionality as a member of the

BFRB community, and the insight that this provided, marks another difference between the psychiatric research and our fieldwork approach.

In contrast to the existing psy literature, we call for a more complex view of what a "family" is and what happens inside of them. Specifically, our ethnographic approach puts into question the premature uses of structured methodologies to assess "family functioning" in relation to BFRBs. Many interfaces of hair pulling and family relations are not visible in any of the existing structured assessments of "functioning." These assessments of functioning only work in cases when the condition is clearly diagnosed and when other family members are aware of it. It does not work when the condition is undiagnosed and when sufferers successfully conceal the condition from others in the family. We also show that the existing psychiatric research has not yet developed a sensitivity for a range of issues that we identified through ethnographic work, including the importance of pleasure to the hair pulling experience, which often goes against family perceptions of the disorder as harmful or destructive; the tensions that arise from other family members either *not knowing* or *not wanting to know* about trichotillomania; and the extremely close ties among fellow BFRB sufferers that may be stronger than ties to one's family members.

People's attempts to deal with BFRBs on a daily basis were frequently affected by reactions from family members who did not fully comprehend what their loved ones needed or wanted. By following the experiences of families living and dealing with BFRBs, we discuss how domestic worlds are renegotiated through support outside the family, and how relatedness through shared experiences can open ways to acceptance and recovery.

PARENTS' RESPONSES TO HAIR PULLING

“Why can’t you *just stop*?”

We begin our presentation of findings by highlighting negative ways in which family members, especially parents, respond to hair pulling: censoring verbal reactions relating to appearance (shaming in front of others), physical punishment, and derisive comments n everyday interactions, such as “why can’t you just stop?” These attempts at “caring” fail because they increase tensions and, subsequently, they increase pulling behavior.

The shame of living with trich can be seen in the silence of people who live with its effects, and within their families. Most people we spoke to admitted that they tried to keep their hair pulling a secret from everybody, not only those encountered in public spheres but even close family members. Some sufferers felt that they concealed the condition so systematically that not a single other family member was aware of it.

The desire to conceal trich from relatives is based on well-founded fears about revealing it. Heather, for example, found out the hard way that sharing with parents did not lead them to caring. During an interview in November 2015, Heather became very emotional describing how her parents had dealt with her hair pulling; she felt that their long-term silence on the topic had created a barrier between them. On one occasion, Heather had tried to break this silence with her father, a medical doctor who she thought of as someone who could understand her and offer support. She was in her twenties when she read a magazine article about trichotillomania and realized that there was a medical name for her hair pulling. She picked up the phone to tell her father about what she found, in the hope to be seen and to connect with him about the condition, but her attempt failed. He did not want to speak about it further, for fear of “indulging” a destructive habit:

> The first thing I did was ring my dad, and up ‘til that point we hadn’t ever addressed my trich, never spoken about it even though there was one period in primary school where all of this was gone [she circles the crown of her head]. And I said to my dad—and I was feeling really brave—I said: ‘you know I do this thing?’ And he said ‘yes,’ and I said ‘well, it’s got a name, can you do some research for me, can you ask some people?’ I phoned back a few days later to ask if he had done some research, and he said ‘no, no, no, no, your mum says not to indulge you.’ [She begins to get tearful and her voice wobbles]. So I don’t talk about it with them. And I don’t [now] and I don’t think I will [again]. There’s no point.

We found that this kind of silencing and wilful ignorance from family members is common. We asked Olly, a Scottish man in his thirties, if he ever talked about it with his parents and he said “no.” He described how he had mentioned to his father that he is still pulling his hair out, and his father responded by a brusque refusal to engage: “What? What’re you doing that for? That’s *stupid.*”. His mother, present at this conversation, neither intervened nor offered any support.

Siobhan, 31, from Edinburgh, had similarly negative experiences telling her family, and got the feeling that “they don’t really know what I mean, and they never ask me about it.” She gave us an example of her sister’s wedding, when she was being prepped with the other bridesmaids and had to disclose to all her sister’s friends the state of her hair. Embarrassed and upset, Siobhan’s mother told her “please don’t make a scene!” Siobhan now avoids conversations about her hair with family members.

When discussing these experiences of silence, many of our informants believed that the silence was linked to inaction, that family members simply did not know what to *do* and, therefore, did not know what to *say.* In turn, silencing was perceived as a lack of care, and

fuelled a sense of deep isolation and embarrassment. It has been argued that silence and secrecy is part of everyday domestic lives, indeed that domestic lives can be more harmonious when they are protected by secrecy (e.g., Chapman 2006, Smart 2011). For our informants, keeping their hair pulling a secret is their way of reducing the stigma inflicted, or feared to be inflicted, by family members. Remaining silent is, therefore, a way of reducing the risk of stigmatization connected to the disorder. However, people's memories of silent parents who appeared to ignore their child's suffering reinforced negative feelings. These "silent memories" (Kidron et al. 2009) act as a form of communication between parents and children, an expression of how hair pulling is viewed in the household and in everyday life.

Silence and secrecy are not the only ways of dealing with hair pulling. In many cases, hair pulling leads to open and direct conflict between parents and children. For example, Dhaya was born in the UK to Indian Sikh parents, and began pulling out her hair at age 11. She told us that her hair pulling was considered to be the same as hair cutting, which was forbidden as a Sikh, and so she was punished severely for it by her mother. Dhaya is now in her thirties with two daughters of her own, but her relationship with her mother remains fraught. Her mother's negative reactions to hair pulling appear as a life-long trigger for her low self-esteem which has influenced her perceptions on motherhood:

> It's just something about being a parent that makes you realise it's not just you anymore, you're responsible for another person, and I felt like I had to overcome [hair pulling] for them… also it's bloody annoying because when they're born, they come out with so much fucking hair! It's like, you can't get away from it. So, they come out with a shit load of hair, and then you get all the religious stuff from family to do with hair, and it's like, I'm in the

middle and it's all about hair. And the one thing that I've got just happens to be a disorder about hair.

Dhaya's experiences of trichotillomania were often mirrored in the lives of her daughters, as Bradley observed while staying in her home. One afternoon, Dhaya's girls were watching *Tangled,* Disney's version of the Rapunzel fairy tale, and her oldest daughter asked if her next birthday party could have a *Tangled* theme. Looking at Bradley, Dhaya rolled her eyes and said: "Hair, hair, hair, it's all about hair!" Dhaya had short-cropped hair, but her daughters carried their hair in long, perfectly maintained plaits, in accordance with Sikh tradition. When asked if it was for religious reasons, Dhaya emphasized tradition: "It's more that it's what I've always known. In my whole family, I am the only one who has ever had short hair. That, and I just can't be bothered with the headache from my mum asking why I'd cut their hair."

Dhaya highlights several important points about trichotillomania and family life. Firstly, the punishment she experienced from her mother as a Sikh girl who was unable to keep her hair long shows how cultural expectations of hair affected her family's responses to trichotillomania. Secondly, her transition from "hair pulling daughter" to "hair pulling mother" illustrates the ways that life course events can alter perceptions of self and influence decisions in trying to overcome a repetitive behavior. Thirdly, Dhaya's memories of childhood and her own mother, combined with new experiences with her daughters, shows the way that experiences of trichotillomania are intergenerational, and continue to affect relations between people over time.

In this section we have described the negative reactions from parents dealing with trichotillomania and their subsequent effects on their children. For many people, the silence

towards hair pulling from parents reinforced the shame they experienced with their BFRB. In turn, however, this silence could make people feel unsupported from their closest kin. Although silence, ambivalence and punishment could be considered "normal" aspects of domestic life, these responses can worsen the experiences of the disorder. These examples show a darker side of kinship (Geschiere 2003) and support newer kinship studies that trouble assumptions of families as invariably supportive and harmonious (Edwards and Strathern 2000; Reece 2015). It is unlikely that parents do this intentionally; instead these responses are influenced by misunderstandings of the disorder and lack of support from health care services. In the next section, we explore parents' perspectives of trichotillomania, and the differences between mothers and fathers dealing with hair pulling children.

Sadness and anger

Although a few of our British informants had received positive support from their families, the majority had not. In contrast, the parents we met at TLC conferences appeared to have much more positive responses, by attending workshops and learning about BFRBs to improve their methods of caring for their children. Despite the availability of these resources, parents still described the sadness and anger that they experienced on a daily basis, which was often split along gendered lines.

Mandy, a mother from New York City, attends the TLC conference annually with her teenage daughter Frankie. We met Mandy at the April 2016 Conference in Dallas, Texas, and asked about her experiences with trich. Frankie had been pulling her hair for three years, and Mandy had taken an active role in supporting her daughter, attending support groups and conferences, and seeking advice online. She began by talking about the parent-only Facebook

support group that she administrates: “it’s just a place for parents to go and vent and cry and rage or share stories of success or methods… so it’s a nice place for everyone to convene in a safe environment where they’re not feeling judged.” When asked what the most common issue is that comes up on the Facebook group, she replied: “Sadness. That our kids are afflicted with this, and we don’t know how to help them, and often times they don’t know how to help themselves, and sometimes they don’t *want* to help themselves, sometimes they are adamant and defiant about receiving help and you realise that it’s their journey to be on, it’s not ours.”

For parents dealing with the early effects of trichotillomania, the visible loss of hair in their children connects with their sense of grief at losing an element of their child’s identity. Mandy described the “mourning” and loss that came from discovering that her daughter was pulling her hair out. She recounted how she would routinely brush Frankie’s hair before bed, and in the early times of the disorder, she would sob each night as she did this. She admitted that now she realises how this reaction might have made Frankie feel even more ashamed and guilty, but at the time, she was still “grieving” too much. As Mandy said, it was not exactly the *hair* she was mourning as a mother, but the lack of awareness and being “blissfully unaware” that anything like this could happen to them.

Kinship has been described as a “mutuality of being” in which parents and children can share affective and bodily experiences of both joy and sadness, and the “experience is more than the individual” (Sahlins 2011:3). The sadness and grief Mandy described suggests a “mutuality of being” between her and her daughter. As she watched Frankie’s hair diminish, Mandy also experienced a sense of loss. But there is also a disconnect between these experiences, and she realises it is a journey her daughter must overcome on her own.

Her sadness is also fuelled by the shock of having to deal with trichotillomania when she had never heard of the disorder before, and felt unprepared on how to handle it as a parent. This acts as a reminder of how awareness of mental illness can directly influence the families of those affected.

Mandy's shock and grief towards hair pulling was echoed by other parents, like Camila, mother of 13-year-old Megan, who we interviewed at the Behavior Therapy Center in Washington, DC in April 2016:

> I didn't know *anything* about it. And obviously, as a parent, you start to second-guess yourself, you know, 'what did we do *wrong?*' You know, if you're not experienced with it, then you're just floating through and trying to figure out how to deal with it… But she's learned to deal with it in the social aspect… But I worry about the mental aspect, the physical aspect of it. And obviously, she's in these critical years as a *girl*, it's tremendously hard. And for the longest time I was taking ownership of it and just trying to make it *my* problem, and that was really hard, I mean, just the stress and the frustration. Because you want to talk to them about it, but they don't want to talk about it. And you want to help them and you want to make them stop, so it's like you go between being soft and gentle and 'what can I do for you?' to being angry because you're like 'why can't you stop?' It's such a struggle, because you're feeling helpless because you can't help your child and that's *really* difficult.

Camila reinforces the idea that mothers feel a mutuality of being towards their daughters, as she tried to make it "her problem." But like Mandy, she realised "it's their journey to be on, not ours." Disconnecting from the subjective experience of their child became part of the support process. Camila also had similar experiences of anger, despair, and helplessness, stemming again from a lack of awareness into the disorder. While she tried to be supportive,

ultimately she gets frustrated and exclaims, “why can’t you stop?” As we have shown earlier, this lack of understanding into the embodied experience of hair pulling, and the pleasure that people can get from BFRBs, is an aspect parents struggle to comprehend. Camila emphasized feminine appearances and was concerned about the impact of trich on her daughter’s “critical years as a *girl.”* The role of gender to hair pulling experiences is important, and requires deeper exploration, but in relation to parents and children, we came across frequent references to gender differences and expectations.

Our respondents frequently mentioned different ways of responding by fathers and mothers. Mothers were more active support people and fathers tended to keep a distance. As Mandy said in relation to a BFRB group on Facebook: “One of the biggest issues that comes up is the dads, dads just don’t understand it.” According to her, only a small number of fathers participated in online groups compared to mothers. Mandy theorized that this gender imbalance was due to most BFRB sufferers being female; hence it came more naturally to mothers to be engaged in help seeking for their daughters: “The majority of our members, their children are girls, so it’s the mother who’s grieving the most over what’s happening.” Although many young boys do suffer from trich, Mandy thought that if a son pulled out his hair, it was easier to conceal: “I don’t think it’s as shocking to see a boy with his head shaved. You know, society, when they see a girl with her head shaved … it’s a whole gender thing.” Thus, for parents, society’s gendered beauty ideals shape responses to trichotillomania and influence the level of suffering experienced. These gender norms also affect the ways that parents mourn for their children’s hair loss.

In relation to fathers, our informants highlighted that the lacking involvement of fathers came hand in hand with traditional gender roles of fathers as material providers rather

than as emotional carers. Mandy's husband was not present at the TLC conference in 2016, and when we asked Mandy how her husband had dealt with their daughter's trich, she said that emotionally he was "just not an active force in any of this." According to her, going to a TLC conference meant making oneself emotionally very vulnerable, and Frankie's dad was not able to do so. Yet he was happy to book and pay for his wife's and daughter's travelling to the annual BFRB family conferences: "He's the first one to get online and book our flights for us. And that's his way of supporting us."

Other respondents did not divide fathers and mothers by their levels of emotional intensity, but by the kind of emotion. Mandy, for example, saw typical differences in the emotional responses to a child's BFRB: "The dads tend to be more angry about it, and the moms tend to be more sad about it. You know, there's anger in the mom groups too, but it's fleeting." But not all fathers were either distant or prone to anger. At the BFRB conferences, a few fathers could be spotted. Even conference organizers acknowledged that fathers might have additional struggles when dealing with their children's BFRBs, and scheduled a whole workshop for "men only." On the last day of one of the conferences, Bradley had breakfast with the Maxwell family. Asking Mark, the father of 12-year-old Tiffany, how he experienced his first time at the TLC conference, he said that a new awareness of other sufferers has made him change his view of his daughter as well as of himself as a father:

> I've learned some things, I think what I struggled with at first with the disorder initially, y'know as a father right, you just wanna fix everything, so for me to look at her and say, 'Hey Tiff stop doin' that,' that should be enough. But that's not the way it works. And it took me a little while to learn that. And I think once I learned that I personally went through a pretty significant stage of guilt, y'know for my own career growth I've moved the family around

over the last six years, and those coincided with the disorder starting and then getting progressively worse, so for me it was the associating of 'this leads to that' - I did this to my daughter. So those are just things that I had to work through, and now I think I'm in a pretty good place, I don't look at her anymore and just see the bald spot, or see the wig, or see the no eyebrows or no eyelashes, I get to look at Tiffany now and just see all of the wonderful things that are her.

Our findings on father/mother differences bear a certain resemblance to some of the assertions in the psychoanalytic literature on hair pulling, which also describes fathers as emotionally distant. Yet our respondents did not say anything that would have supported the stronger claims in some of the psychoanalytic literature about father/mother/child constellations, for instance, that a child's hair pulling expressed frustration with reversed parental roles of "highly ambivalent and aggressive" mothers and "passive and inadequate" fathers (Greenberg and Sarner 1965:489), or that a daughter's hair pulling reflected unresolved identification with the mother that turned into self-harm (Buxbaum 1960). Instead, gender roles are rendered more visible through experiences of trichotillomania. We also highlight how the lack of awareness of BFRBs makes these disorders harder to deal with for parents, and in turn, connecting with the "TLC Family" can bring much-needed support for parents and children.

"Like one big family:" Relatedness in BFRB support groups

Relations between hair pullers and their parents are, we have argued, fraught with many misunderstandings, tensions, and failed forms of care. These intra-family difficulties contrast

with the kin-like bonds that groups of fellow sufferers can establish with each other. As a result, these support networks can create better ties within the close family.

TLC is the world's leading organization for trichotillomania and related disorders. Although based in the US, they support families and individuals all over the world, providing information and awareness on BFRBs. A key part of their work is running annual conferences across the United States to bring people together. These are three-day events for parents, adults, children, clinicians and researchers from across the globe, and aim to inform and connect people living and working with BFRBs. When Bradley visited the conference for the first time in April 2015, she saw hundreds of people of all ages meeting for the first time in this remarkable and emotionally charged situation. She was told: "There are no handshakes in this community, only hugs." There is also an interesting connection between the professionals who attend the conference, for whom the weekend is the "highlight" of their year, and several of them also referred to the community as "like one big family." For them, there is something unique about TLC, as one clinician told us: "There are other organizations that serve sufferers and professionals, TLC is not the only one. But none have so successfully merged, and this one is very special, almost every professional that has become involved with it feels that special connection between the consumers and the professionals, that there's less of a divide, that people feel very comfortable." During the 2016 Conference in Dallas, we spoke to a number of researchers and clinicians working with BFRBs, one of whom was running a workshop on the latest research findings for parents and young people. He told us that at the end of his workshop, he asked the audience what was the most valuable thing they had learned this weekend? He was expecting an answer relating to current research and scientific findings, but instead several people responded: "Just knowing I'm not alone any

more", "realising there are others out there just like me." He told us he was shocked, and until then had not realised the "power" that these relationships could have.

For most people, TLC conferences are transformative, and mark a transition from isolated suffering into shared acceptance. At the TLC conference 2015 we observed many cases of people with trich opening up and building relations with others with a level of ease and comfort that they hardly ever experienced before. For example, on the first day of the conference, ten-year-old Tiffany sat slumped over the breakfast table. She stared blankly at her plate while her mother talked to Bradley. The next day, Tiffany had already formed friendships with other children, she smiled confidently and hurried away from her mother in the morning to meet new friends. Soon after, Tiffany went swimming with other children, an activity she usually avoided due to her trich. On the final day of the conference, Tiffany and her mother joined Bradley to say goodbye, the ballroom was filled with people hugging, and crying, sad to be returning to daily life without this support and freedom.

Bradley returned to meet Tiffany and her mother, Penny, at the next TLC conference in Dallas in April 2016, and this time Tiffany's dad, Mark, also came along. Penny and Mark spoke about the kind of family-like ties created through the conferences and how they wished they had people with similar experiences around them in their regular life. The proximity of support networks is important for Tiffany and others. They express a loss for their "TLC family" in between meetings, who they feel can offer them a different form of care than their immediate families. That difference is acceptance, understanding and belonging. The physical distance between people acts as a reminder of the isolating nature of this condition, and the silence that surrounds it.

There are major differences for people living with BFRBs in the United Kingdom and in the United States. The presence of TLC as a leading organization has created community networks for those who are otherwise isolated. As mentioned, the lack of public awareness on hair pulling means that people often spend years thinking they are alone in their experiences. During interviews with people in the UK, this moment was described with utter amazement "I couldn't believe it was a thing!", "I realised I wasn't the only one!", "It had a name!", "I realised I'm not alone". This sense of being alone strengthened the bond between people when they met for the first time, which many people described as "it's like we've known each other forever."

In Solomon's (2012) account of parents who struggle to relate to the experiences of their children, he notes how new communication technologies help to create "social kinship" for people who are often excluded from close kin relations. Discussing the increasing medical knowledge and attempt to eradicate and "fix" the conditions in his focus (such as deafness, Down's syndrome), Solomon argues that social kinship "is making disabling conditions easier to live with just as medical progress is eliminating them" (2012:20). This confluence between "cure" and "care" is visible in families' experiences of trichotillomania, and is something we will return to. It could be argued, however, that "social kinship" reinstates a questionable dichotomy between social and biological kinship (Schneider 1984).

"Relatedness" has become a useful term for comparing a variety of cross-cultural social relations (Carsten 2000). While "relatedness" may be too broad a concept (Holy 1996), we find it more relevant to our examples than concepts such as "social kinship," "fictive kin" (Nelson 2014), or "biosociality" (Rabinow 1996). "Relatedness" captures the way that the TLC conferences shape family-like connections that can bridge vast spatial distances. It helps

to show how people in support groups settings feel connected through a shared sense of suffering. Emily Martin (2009) has also highlighted the value of support groups in helping people with bipolar disorder feel a sense of belonging. Psychologists even argue that a three-day conference with fellow BFRB suffers could be as therapeutically effective as a ten-week course in cognitive behavioral therapy (Rehm 2017).

Conversations with our informants in the UK who attend support groups reiterated this, but people with BFRBs do not always have the opportunity to meet regularly. Since TLC conferences only happen in a delimited time and space, they also remind people of how isolated they feel in their everyday lives. In an email from Tiffany Maxwell to Bradley following the conference in 2015, she wrote: “When I got back from DC I was pulling a bit more. I think it is because I’m not around my TLC family anymore… I just wish there was someone closer to me who has trich”. Thus, while being at a TLC conference can help people reduce their urges to pull, this efficacy is often short-lived if these support networks do not continue at home.

Care and recovery is complex for BFRBs, as it holds different meanings to different individuals. For many, the aim is to be pull-free altogether, and any form of “relapse” or “pulling episode” will be considered a failure. From conversations with parents and family members, it seems that often this is the ideal form of recovery for them too, particularly in young children and teens, whereby parents hope that one day they will stop completely. However, total cessation of pulling behaviour is unlikely for most, and despite TLC’s mission to “find a cure,” their conferences showed that recovery often means the acceptance of living with a BFRB. While many of the people who seek out fellow sufferers will never be pull-free, the feeling of being part of the TLC family gives them strength to get through their daily

lives with less friction and anguish. Recovery for them means accepting this disorder and reducing the isolation and shame connected to it.

CONCLUSION

Through ethnographic examples, we revealed how people living with trichotillomania recall how family members reacted with repulsion, shaming, and sometimes even physical abuse to their hair pulling. For our respondents, these experiences could influence later life experiences of the condition, often worsening its effects and increasing the shame associated with this complex disorder. Many sufferers described an uncaring lack of response to their condition. The silencing of the problem could be understood as a form of helplessness in the face of a perplexing disorder, but their dismissal of hair pulling could deepen the loneliness of those affected and exacerbate the embarrassment of their “abnormal” behavior. It was evident that family members who have access to support networks like the TLC Conferences in the US find it easier to cope with the disorder. Yet even with more understanding and better support, relatives continue to feel loss and grief about the situation, and many remain on the lookout for a cure. The differences in experiences of mothers and fathers, as discussed earlier, also show the gendered aspects of care for families dealing with mental health concerns in young people, and is an aspect that deserves more attention in the future.

The focus of leading organizations such as TLC into potential cures for trichotillomania and other body-focused repetitive behaviors brings family relations to the fore. Ethnography shows that affective dynamics in the domestic sphere make a significant difference to how people cope with BFRBs, and that there are many dimensions of relatedness that are not captured in structured assessments of family functioning. We have

also highlighted the kind of relatedness allowed by discovering that the condition "has a name" and that there are others who share the diagnosis. Thus, in contrast to the often harmful reactions from close family members, meeting and connecting with others who have the condition creates kin-like bonds through meaningful forms of relatedness.

The research on experiences of BFRBs remains limited, and family relations are especially lacking. In our research, we discovered that encounters with parents are key to experiences of trichotillomania. This requires more research that can capture the complexities of kinship relations. In this article, we shed new light on the secret pleasures afforded by BFRBs, as well as the complex relations between sufferers, family members, and therapeutic others. Importantly, we have shown that the powerful sense of relatedness that comes about in support groups can be vital to coping with BFRBs, and that ties with other sufferers can open up a sphere of relatedness that may not exist within the family.

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